Review of Seven Year Strategic Plan for the Development of Specialist Palliative Care Services in the Mid West Region 2004 - 2011

Feidhmeannacht na Seirbhíse Sláinte
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FOREWORD

Great strides have been made over recent decades in devising and providing the array of services which constitute 'palliative care'. This progress has emerged from the discussions which have continued in treatment and research circles on how best to cater for those patients for whom palliative care is necessary and appropriate. This debate will continue in the newspapers, popular programmes and learned journals as existing and emerging needs seek better and alternative responses.

Palliative care is now seen as a central element of the health services as witnessed by the Report of the National Advisory Committee on Palliative Care which was published in 2001. Its recommendations constitute the roadmap for the future planning and development of services generally. In the Mid-West Region considerable progress has been made in the provision of palliative care services. Indeed, with the publication of the 2001 report, the basis for the further development of palliative care services in the Mid-West Region was further enhanced. It has to be noted that an earlier joint Mid Western Health Board/Milford Hospice/Irish Cancer Society report of 1991 had already set the foundations for development of services in the Mid-West.

The Seven Year Strategic Plan for the Development of Specialist Palliative Care Services in the Mid-West Region (2004-2011) is a progressive and ambitious document. As the Review will indicate, very much progress has been achieved and a platform has been put in place for further development and expansion of services. This progress has been made possible by the long-standing partnership between the HSE (formerly MWHB) and Milford Care Centre. The continuing focus on the strategic approach, evidence-based practices, research initiatives, supported by continuing evaluations and reviews have been the hallmarks of what is a progressive and forward-looking service.

In carrying out this Review, my sincere thanks are due to all those listed at Appendix 2 for the very open and helpful approach taken by each in making suggestions and recommendations for the betterment of the service. In particular, I wish to express my thanks to Ms. Carol Murray, Head of Non-Clinical Support Services at Milford Care Centre, for her generous help and assistance to me in the course of this exercise.

It gives me great pleasure to present this Review.

Martin J. Duffy, Ph. D

October, 2011

GLOSSARY OF ACRONYMS

ADL	Activities of Daily Living
CIT	Crisis Intervention Teams
COPD	Chronic Obstructive Pulmonary Disease
CNS	Clinical Nurse Specialist
DoH/DoHC	Department of Health/ Department of Health and Children
FETAC	Further Education and Training Awards Council
GP	General (Medical) Practitioner
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
ICGP	Irish College of General Practitioners
ICS	Irish Cancer Society
ICT	Information and Communications Technology
IHF	Irish Hospice Foundation
IHSAB	Irish Health Services Accreditation Board
MCC	Milford Care Centre
MWHB	Mid -Western Health Board
MWRH	Mid -Western Regional Hospital
NAC	National Advisory Council on Palliative Care
NCHD	Non-Consultant Hospital Doctor
OPD	Out-Patients Department
RCPI	Royal College of Physicians of Ireland
SPC	Specialist Palliative Care
UL	University of Limerick
WHO	World Health Organisation

REVIEW OF STRATEGIC PLAN

1.0 INTRODUCTION

1.1 This document reviews the progress made in the implementation of the recommendations of the *Seven Year Strategic Plan for the Development of Specialist Palliative Care Services in the Mid-West Region* (MWHB: 2004b).

The World Health Organisation defined[1] Palliative Care as:

'…an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications' *(WHO 2002.)*

Another definition[2] is 'the continuing active total care of patients and their families by a multi-professional team at a time when the medical expectation is not cure and the primary aim of treatment is no longer to prolong life. The goal of palliative care is to achieve the highest possible quality of life for both patient and family. Palliative care responds to physical, psychological, social and spiritual needs. If necessary, it extends to support families and relatives in bereavement'.

Specialist palliative care services are those services whose core activity is the provision of palliative care which is provided by an inter-disciplinary team, under the direction of Consultants in Palliative Medicine. It covers the spectrum of services from in-patient hospital care to care in the home.

[1] *Ref: National cancer control programmes: policies and managerial guidelines*, 2nd ed. Geneva, World Health Organization, 2002.

[2] www.eurohealth.ie/cancom/defs.htm

1.2 The *Report of the National Advisory Committee on Palliative Care* (DoHC 2001) (NAC) outlined a vision for the development and enhancement of palliative care services in Ireland.
It set out recommendations in relation to the setting up of a comprehensive palliative care service in each health board area, structured in three levels of ascending specialisation:

- Level one – Palliative Care Approach
    - Practised by all health care professionals
- Level two – General Palliative Care
    - Provided by those with some additional training in palliative care
- Level three – Specialist Palliative Care
    - Delivered by those whose core activity is limited to palliative care.

While palliative care may be provided in a number of settings the Report recommended that a specialist palliative care in-patient unit should be the core essential element of a Level three service. It further recommended that those units should be staffed by medical, nursing and paramedical staff specially trained in palliative care. Those units should furthermore be of sufficient size and scope to meet the specialist palliative care needs of the population. They would be supported by an array of community based services.

1.3 As will be shown below, the former Mid-Western Health Board (MWHB), now subsumed into the HSE since 2005, acting in accordance with the recommendations of the 2001 Report, carried out a needs assessment in its area – *Specialist Palliative Care Services Needs Assessment* (MWHB 2004a) - to establish the level of service provision then available and to identify the gaps to be addressed to achieve the level of services envisaged in the 2001 Report. This entailed widespread consultation with interested parties including the Regional Consultative and Development Committees on Palliative Care. The *Seven Year Strategic Plan for the Development of Specialist Care Services in the Mid West Region 2004-2011* (MWHB 2004b) followed in December 2004.

1.4 The Seven Year Strategic Plan was seen as a collaborative project between the MWHB (now HSE) and Milford Care Centre (MCC). Since 1991, MCC has been regarded as the main specialist resource in the Mid West Region for the development of palliative care services:

'Milford Hospice is now seen as the major focus of the hospice movement in the Mid-West Region, and also a resource centre for the various staffs involved in cancer care. It is the policy of the Health Board to develop its services in conjunction with Milford Hospice' (MWHB 1991:8).

For a fuller background to the development of palliative care services in the Mid-West region see Appendix 7 below.

The partnership arrangement which has developed between the MWHB (now HSE) and MCC has been central to the successful development of services over the years.

In addition to this statutory/voluntary partnership Milford Care Centre has forged links with other voluntary agencies to promote the palliative care agenda in the region. Other partners include The Atlantic Philanthropies, Irish Hospice Foundation, Irish Cancer Society, North Tipperary Hospice Movement, JP McManus Invitational Pro-AM and the many individuals who have made a donation to the Centre. These links, and the funds provided, have contributed significantly to the development of palliative care services across the region on both a project and ongoing basis.

1.5 One of the key recommendations of the Seven Year Strategic Plan was that its progress should be reviewed at an interim stage (MWHB 2004b:41). A decision in this regard was made in early 2010. Terms of reference on the following lines were agreed by the HSE in consultation with MCC:

- Examine and report on each of the recommendations of the Seven Year Strategic Plan
- Appraise the implications of the following documents:
    - Palliative Care Services Strategic Plan 2009-2013: HSE West (HSE West 2008)
    - Palliative Care – A Five Year/Medium Term Development Framework 2009 - 2013 (HSE 2009)
    - Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks (HSE/IHF 2008)
    - Palliative Care for Children with Life Limiting Conditions: A National Policy (DoHC 2009)
- Raise issues for consideration relating to the future planning and development of the service.

1.6 Chapter Two examines each of the recommendations of the Plan. Chapter Three proceeds to examine the implications for palliative care services of the recommendations of the reports listed at 1.5 above. Chapter Four discusses the service development to date and raises issues to be considered in the future planning of the service while Chapter Five makes some relevant observations and conclusions.

1.7 In carrying out this review interviews were held with those listed at Appendix 1. To all those listed sincere thanks are due in view of the very open and helpful approach taken in making suggestions and recommendations for the betterment of the service. The documents listed at Appendix 2 were consulted for advice and direction on policies on palliative care in Ireland and elsewhere.

2.0 REVIEW OF STRATEGIC PLAN RECOMMENDATIONS

Summary The HSE and MCC have made significant progress in addressing the elements of the Strategic Plan. Of the 34 recommendations, 24 have been achieved, 6 are commenced (and well advanced) with 4 requiring further continuing attention.

Recommendation 1 Palliative care services in the Mid West Region should further develop in a planned and co-ordinated manner.

Outcome Acting on the recommendations of the Report of the National Advisory Committee on Palliative Care (DoHC 2001), a Needs Assessment of Palliative Care Services in the Mid-West Region was carried out and reported on in February, 2004. After consideration of the findings of the Needs Assessment by the Regional Development and Consultative Committees, steps were taken to produce a strategic plan for the Mid-West region.

The work to produce a strategic plan was carried out by a group drawn from the Regional Development and Consultative Committees. It set out the areas of priority development to be addressed in a planned and co-ordinated manner following a process of consultation with the various stakeholders in the region. The consultation process was seen as very important in that the views of patients, families, medical and other health service practitioners and the public were deemed essential in capturing what it was that should be provided in a future service. The preparation of this plan involved widespread consultation with the statutory and voluntary agencies with responsibilities for the provision of palliative care. While this process was an exhaustive exercise, it was helped by the longstanding very positive relationship which had developed between those agencies over the years.

Since 1991, it is the stated policy of the MWHB (now HSE) to provide all palliative care services throughout the region in conjunction with Milford Care Centre as the regional specialist service provider.

The Seven Year Strategic Plan for the Development of Specialist Palliative Care Services in the Mid-West Region was published in December 2004. Its recommendations were accepted by the local statutory and voluntary agencies, the health care professionals, the Regional Committees, the Health Service Executive (HSE) and the Department of Health and Children (DoHC).

The implementation of the recommendations of the Strategic Plan has necessitated a continuing and close working relationship between the various agencies, the HSE and the DoHC. This work has entailed the preparation of costed proposals for the various phased developments, submissions on staffing, securing the various approvals from the relevant professional bodies and the submission of progress and evaluation reports as required. All of this work was carried out under the supervision of the Regional Development and Consultative Committees whose role in these matters was pivotal to success and should not be underestimated.

Recommendation 2 Increase the availability of Specialist In-Patient Beds to meet increases in demand for service and bring the region in line with NAC recommendations, e.g. 8 -10 beds per 100,000 population.

Outcome There are now 30 beds in the in-patient unit at MCC. As early as 1977, 9 beds were earmarked by the Little Company of Mary at Milford Nursing Home as a dedicated in-patient unit. In the early 1980s, a replacement 20 bed unit was provided. Based on a joint MWHB/MCC Development Plan, a purpose built 30-bed In-Patient Unit was built in 1999. Due to limited revenue funding, only 20 of the beds became operational in 1999; in 2006 the remaining 10 beds were commissioned.

With a population of 361,028 (Census 2006), 29-36 beds would be required for the Mid-West Region on the basis of 8-10 beds per 100,000 of the population to accord with the recommendation of the 2001 Report. However, it was decided not to increase the bed provision of 30 beds for the Region but to concentrate instead on developing the relevant community-based services as recommended in the NAC Report. As the following paragraphs will show, considerable progress has been made in developing the supporting community services. Towards this end, the necessary capital and revenue resources, including staff and other costs, have been successfully negotiated with the HSE and voluntary sources.

Recommendation 3 Proceed with appointment of Second Consultant Post.

Outcome There are now two Consultants in Palliative Medicine in post, each with majority commitments to MCC and also commitments to the MWRH. The second Consultant was appointed in December 2005 to join the Consultant appointed in January 2000.

Recommendation 4 Specialist Palliative Care services should participate in the development of an accreditation process, which the Irish Health Services Accreditation Board (IHSAB) proposes to extend to Palliative Care Services. This process should involve the development of quality indicators of service.

Outcome Specialist Palliative Care services participated in the development of the *Palliative Care Accreditation Scheme – A Framework for Quality and Safety* published by IHSAB in 2005.

IHSAB initially produced the *Acute Care Accreditation Scheme – Standards & Guidelines* (IHSAB 2004). These formed the basis of the Specialist Palliative Care Standards that were published the following year. Representatives of the Specialist Palliative Care providers in the statutory and voluntary sectors were included on the Working Party and Focus Groups that reviewed the Acute Care Standards and developed them to meet the needs of the sector.

MCC achieved accreditation under these standards in 2007 for a 3 year period. At the time, it was generally accepted that those Standards were the benchmarks against which quality of services and patient outcomes could be measured.

The role of IHSAB was subsumed into the Health Information and Quality Authority (HIQA) in May 2007, which has made a policy decision not to continue with the accreditation process but instead to progress the introduction of a universal licensing system for all healthcare facilities as outlined in the recently published *Draft National Standards for Safer Better Healthcare* (HIQA 2010:11).

Recommendation 5 Specialist palliative care services should promote and participate in the development of quality indicators and outcome measures of service on a national basis

Outcome MCC provides information on Palliative Care activities on a monthly basis in the formats required by the HSE.

Appropriate collection of quality indicators of service provision is essential in order to facilitate comparison across service providers and geographical areas. Participation in the development of performance indicators for Palliative Care services is an ongoing issue, and is one which is currently receiving focussed attention by the HSE and the relevant service providers.

Recommendation 6 Proceed with proposal to secure approval and funding to appoint a third Consultant in Palliative Medicine with the appropriate support of NCHDs and administrative staff.

Outcome Approval has recently been received for the third Consultant post as part of the Development Funds 2010.

The third Consultant in Palliative Medicine will support both the in-patient and community services provided by MCC as well as providing greater linkage with the Acute services of the HSE. The Consultant will provide direct sessional input into St. John's Hospital. The appointment will also allow for development of an OPD service in Milford Care Centre and facilitate further developments in the specialist community teams, with increased consultant input to the Hospice at Home Scheme and increased involvement with the University of Limerick (UL) Graduate Entry Medical School.

Recommendation 7 Secure funding to develop Specialist Palliative Care Teams in each of the three HSE Community Care Areas with specialist paramedical input to the Acute Hospitals being channelled via the Community teams.

Outcome MCC's Community Service commenced in 1989 and continued as a specialist nursing service until the early 2000s. Under the umbrella of an expanded service, MCC introduced Care Assistants into the service in 2003/4, initially operating as a pilot scheme within a six mile radius of Limerick City. The expanded team continued working closely with the general practitioner and community nursing services. In 2006, an application for funding was made to the HSE and Atlantic Philanthropies to expand that pilot scheme into a full multi-disciplinary service working across the region. Atlantic Philanthropies agreed to fund a number of posts to the end of 2010 with the HSE funding the balance. This arrangement allowed the service to be expanded on a phased basis with it becoming fully operational in 2009.

A recent agreement was reached between HSE and MCC to co-fund the full costs of this service, commencing in December 2010, on an agreed sliding scale basis, arriving at the situation whereby the HSE will be funding 80% of the ongoing revenue costs as from 1st January 2014 with MCC funding the remaining 20%.

The Hospice at Home Service is an important new initiative. The development of enhanced multi-disciplinary specialist palliative care services in the community is designed to meet the wishes and needs of patients to be cared for, and to die, in their own homes. It also allows palliative care patients in other healthcare settings such as Community Hospitals, Nursing Homes, etc, to be supported by the Milford specialist community team. The appointment of the third Consultant will provide additional medical involvement. Important developments have also taken place as part of Hospice at Home in conjunction with the Irish Cancer Society (ICS), in providing additional twilight and night nursing support, supplementing the existing service available at night and over weekends. This has involved integrating the administration of the ICS Night Nursing Service into MCC's Hospice at Home Service on a pilot basis as from January 2010.

The Hospice at Home service is a welcome development for patients and family members. The service seeks to meet the holistic needs of patients and family members and to ensure that the concerns and questions, at what can be distressing times, are adequately addressed. Integral to the development of this service have been the major efforts made to ensure that it is integrated with the rollout of the Primary Care Network of the HSE. The service also provides essential support to the families of patients concerned. The key role of general practitioners is pivotal to the effective operation of this service in terms of their availing of and referring patients to it on a timely basis.

A requirement of the Atlantic Philanthropies grant was that the Hospice at Home project should be externally evaluated and the University of Limerick has been commissioned to review the project. As part of the process the views of service users, their families and carers, MCC staff and those working in Primary Care Teams will be sought. The evaluation report will be published in late 2011.

Recommendation 8 Provide a dedicated bank of equipment in each Community Care Area which is appropriately accessible. There should be a budget for the repair, replacement, storage, cleaning, pickup, delivery and installation of equipment.

Outcome The HSE has the primary responsibility for the provision of aids and appliances in the community and has developed an aids and appliances depot in each county through which it manages its stocks.

Discussions have been held between the HSE and MCC Therapy Managers regarding the availability of equipment and prioritization arrangements for palliative care patients. MCC has a small budget for equipment rental in limited circumstances to assist with early discharge of patients.

Recommendation 9 As part of the function of the Development Committee, an annual report on palliative care activity in all settings should be completed.

Outcome Since 2004, MCC prepares an annual report on its activities. It is published and is available on the Centre's website[3]. The Regional Development Committee for Palliative Care, HSE West also prepares an annual report, which includes activities in the Mid West region.

It is a condition of the annual service arrangement between the HSE and MCC that standard information is provided in the interest of research, epidemiology and general management purposes. It also accords with good governance developments which promote transparency and openness.

Recommendation 10 Extension of existing buildings at Milford to accommodate proposed developments.

Outcome Purpose built accommodation was planned to facilitate a new education/research unit, an increase in medical staff, out patient clinics, a palliative care day unit, specialist community personnel, an ADL assessment area, the base for the Hospice at Home service, increased medical records and equipment storage facilities.

This Capital Development Project commenced in 2007 to provide the additional accommodation. The project was completed in 2009 and was co-funded by the HSE, and MCC, supported by its voluntary funding partners.

Recommendation 11 In light of the Health Services reforms on 01/01/05, consideration needs to be given to ways to ensure the optimum integration of Specialist Palliative Care Services within the Primary Community and Continuing Care Directorate and in its daily interactions with the National Hospitals Office.

Outcome MCC has representatives on the Regional Development and Consultative Committees for HSE West. Members of staff of the HSE and MCC have participated together on a number of committees to develop initiatives, proposals and position papers to enhance collaborative working arrangements and standardise processes across the Region. Linkages are also being developed with primary care teams and their Community Intervention Team counterparts.

Links with Acute services are maintained through the Consultants in Palliative Medicine and pharmacy staff who are HSE employees working between the MWRH and MCC. In addition there is regular contact between senior managers in both locations on relevant issues.

There is a general policy towards creation of effective working relationships in order that the palliative care ethos is integrated seamlessly into the wider health service in the best interests of patient care.

[3] www.milfordcarecentre.ie

All of the above will need to be considered under the HSE's developing Integrated Services Framework.

Recommendation 12 Develop a communication link between the Specialist Services and the Community Support Bed network.

Outcome A Consultation Forum involving MCC personnel and the Community Support Bed Network was established in 2005. It has been expanded to include Clinical Nurse Specialist (CNS) staff in the Acute Hospitals and additional representatives from MCC. This forum will be reviewed on an ongoing basis.

Recommendation 13 Identify means of improving palliative care services delivered to patients in acute hospitals. Pay particular attention to means of communication and accommodation available to facilitate more privacy and dignity in communications with patients and their families in acute hospitals.

Outcome The MWRH is participating in the Hospice Friendly Hospitals Programme on a partnership basis with the Irish Hospice Foundation and MCC. As part of the reconfiguration process, it is seen as best to install national standards to provide appropriate facilities to ensure dignity and respect for patients at all times. It is being done in conjunction with St. John's, Ennis and Nenagh General Hospitals, Community Hospitals and MCC's services.

The MWRH has moved to Phase 2 of the Hospice Friendly Hospitals Programme, and an End of Life Project Coordinator was appointed in January 2011 and is based in the MWRH. The *Quality Standards for End-of-Life Care in Hospitals* (IHF 2010a) and the final report of the first *National Audit of End-of-Life Care in Hospitals in Ireland* (IHF 2010b) were launched in May 2010.

Recommendation 14 Improve the current level of staff support systems for all staff working in palliative care services.

Outcome There is a part-time clinical psychologist post in place at MCC to provide a staff support service which extends to induction of staff and staff training such as stress management. The appointment of a psychologist to staff support provides the necessary back-up to assist and support staff in their roles. This is in addition to the intra-team supports such as debriefing, etc. The availability of comprehensive staff support structures is deemed most desirable to assist staff in responding effectively to difficult situations.

Recommendation 15 Continue negotiations to secure resources to provide a dedicated palliative day care service at Milford.

Outcome A 10-place Day Care service has been operating two days per week for patients coming from within a 15 mile radius. Additional facilities were provided as part of the Capital Development Project completed in 2009. Funding has been provided to expand this to a 3-day week service from December 2010 and to change its status to that of a specialist palliative care service.

A Day Care Liaison Co-ordinator has been appointed as part of the Hospice at Home initiative to work with existing Day Care Centres for Older Persons throughout the Mid West so as to facilitate patients unable to attend MCC services because of distance, where possible, to attend their local established Day Care Centre, with assistance from MCC Hospice at Home staff. A Directory of Day Care Services has been developed by the Co-ordinator, in conjunction with these Day Care Centres, and was launched in early 2011.

Recommendation 16 Establish Regional Palliative Care Outpatients Service at the MWRH and Milford Care Centre. Determine the feasibility of, and requirement for, additional outpatient services in the other acute hospitals.

Outcome An OPD service is operational at the MWRH since mid 2006. Facilities to provide OPD service on MCC campus were included in the Capital Development Project completed in 2009. The recently approved third Consultant post will facilitate the opening of the MCC OPD clinics when appointed.

Recommendation 17 Develop a Regional Lymphoedema Management Service.

Outcome Staff members at MCC have been trained in Lymphoedema management and a limited service is provided in MCC. A new Out-Patient Clinic Room has been developed at MCC as part of its recently completed Capital Project. Further development of this service will take place at MCC as resources permit.

Recommendation 18 Further develop the relationship between Palliative Medicine and the Radiology Department.

Outcome Liaison arrangements in the form of weekly multi-disciplinary team meetings have been developed between the Consultants in Palliative Medicine and those in the disciplines of Medical and Radiation Oncology and Radiology.

Recommendation 19 Increase representation and access for patients with non-malignant illness to palliative care services.

Outcome Access to Milford's Specialist Palliative Care Services is based on need and not on diagnosis. MCC accepts referrals of patients with non-malignant diagnoses. There is a general aspiration that all patients, irrespective of diagnosis, will have equal access to palliative care services.

The recommendations of the report entitled *Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks* (HSE/IHF 2008) are being examined. This is the 'Extending Access Report' regarding non-malignant conditions which promotes the development of palliative care service responses to those with non-malignant life limiting conditions, primarily COPD, dementia and heart failure.

The Report of the Working Party entitled *Palliative Care for Children with Life Limiting Conditions* (DoHC: 2010) will be studied to see how best to respond to its

recommendations so as to provide strong links between local and national paediatric services, the primary care teams and the specialist providers of services.

Recommendation 20 Ensure staff are adequately trained and equipped to provide care for increased numbers of patients with non-malignant illness.

Outcome The Education, Research & Professional Development Service at MCC runs a range of courses, including courses by distance learning, to facilitate staff to enhance their skills.

All patients irrespective of diagnosis will receive the highest quality of care. It will be necessary to periodically ***c***onduct a review of the skill mix and expertise of staff working in the specialist palliative care services

Recommendation 21 Further development of a network of Community Support Beds so that any individual shall be able to access a Community Support Bed within a 25 mile radius of their home.

Outcome As part of the development of palliative care services, the identification of step-down beds was seen as a high priority. Satisfactory progress has been made to date.

There are two 'intermediate' (step down) beds allocated to palliative care in the MCC Nursing Home. HSE and MCC financially support 5 public beds in Cahercalla Community Hospital. There are also 12 intermediate beds allocated by the HSE in its units in Ennistymon, Raheen, Kilrush, Nenagh, Thurles and Roscrea for patients needing palliative care (see Appendix 5 for activity information).

The distribution of these beds supports the discharge of patients back to their local communities. Furthermore, the availability of these beds reduces the number of admissions to Acute Hospitals in the region, along with ensuring that more patients can exercise their preference of being cared for in their own homes. An evaluation of the service and its associated costs is required to indicate areas of possible greater efficiency and throughput.

A 4-bed intermediate facility has been developed in Newcastle West which was primarily funded by the HSE with a contribution from MCC. However no additional revenue funding necessary to commission this new facility has been made available at the time of writing but it should be noted that this project is included in the HSE National Service Plan 2011 (HSE 2011:48). As an interim measure, there is a general level Palliative Day Care service being provided. Funding for this service has been made available by the Friends of St. Ita's, whereby MCC employ the staff who, in turn, report to the local HSE Nursing Manager. This is a 3 year agreement, which is subject to annual review.

All these facilities are 'connected' back to Milford as the recognised 'hub' of palliative care delivery in the Mid West. There is future capacity for integration of services, including these beds, with the developing Hospice at Home service. Staff in

these Units are offered the opportunity to attend education courses in MCC and staff from MCC have provided locally based education and information sessions

Recommendation 22 There should be ongoing liaison and consultation between community specialist palliative care teams and the primary care teams.

Outcome An integrated and seamless package of care for individuals accessing palliative care services which avoids duplication or gaps in service is most desirable. In association with the Acute services, Crisis Intervention Teams (CIT) are being developed to provide home visits within hours of patient discharges, thus providing linkages with primary care personnel. These teams link with MCC's Hospice at Home service. Such a seamless integrated model will be developed across the health system.

Considerable emphasis is placed on maintaining the independence and integrity of decision-making by individual patients.

Working relationships between the HSE primary care teams and the MCC multi-disciplinary teams are developing with greater integration of services and agreement on working protocols.

MWRH linkage with the palliative care service is through both Consultants in Palliative Medicine and through Clinical Nurse Specialists in each of the Acute Hospitals. There are 6 Clinical Nurse Specialists in the acute hospitals with three CNSs in MWRH and one in each of St. John's, Ennis and Nenagh General Hospitals.

Representatives of MWRH and MCC sit on the Palliative Care Consultative Committee for HSE West. It deals with the development of services, the roles of the hospitals and home care teams, also specific areas such as education, pharmacy and aids and appliances.

Representatives of the MWRH and MCC also sit on the Palliative Care Development Committee which has a planning and advisory function on resource utilisation for HSE West.

There is a Consultation Forum in place for MCC staff, Acute Hospital CNSs and staff in the Community Support Bed Network. There is an annual study day for GPs. MCC Line Managers have worked with their HSE colleagues to develop protocols and guidelines to support integrated working arrangements. Links have been established with the HSE's Transformation Development Officers and operational Primary Care Teams.

Recommendation 23 Commitment to facilitating a standard of excellence in education and research in palliative medicine/care which matches and exceeds international guidelines**.**

Outcome In 1989 the Education Department was established, initially providing education in bereavement support in association with the Social Work team. The Education Department has grown steadily and in 2007, following a review of

structures in Milford Care Centre, its function was examined. As a result of this review, professional development, research and evaluation were merged together with education, as is the case in some other hospices in Ireland and the UK. Since then, the Education, Research and Professional Development Service has become a leading provider of palliative and clinical skills education and supports individuals working in the organisation to engage in research and evaluation at both local and national levels.

Over the past three years, the service activity levels have increased by approximately 900% and the service has been nationally recognised as the Irish Co-ordinating Centre for the European Certificate in Essential Palliative Care. MCC staff work closely with the University of Limerick to facilitate student placements and to engage in education and research across both sites. MCC is a Consortium Member of the newly established All Ireland Institute for Hospice and Palliative Care. The Head of Education, Research and Professional Development chairs the HSE West Palliative Care Education Forum that convenes six times per year (by teleconference) and is a member of a number of national groups and projects.

Staff working in the service have successfully applied for grants to drive developments in education and research nationally. The service has recently launched E-Life[4], the first hospice-led electronic learning environment for palliative care in Ireland. The Centre also provides the only 3-day Advanced Communication in End of Life Care programme in Ireland. As a result, the Education and Research Service in MCC is to the forefront in delivering high quality and creative education programmes, which are responsive to meeting the ever changing needs of the sector.

Over the coming two years, the service will focus on developing a training function and is seeking quality assurance through FETAC to ensure that staff working at all levels have access to training that meets the requirements for them to excel in their particular roles. Professional practice entails the monitoring and the integration of education and research forums into the daily routines of all disciplines.

Recommendation 24 Determine the feasibility and organisational benefit of pursuing multi-disciplinary practice development in all aspects of palliative care in conjunction with the education department.

Outcome Multi-disciplinary team working arrangements have been enhanced over the lifetime of the Plan. Multi-disciplinary team meetings and *Meitheals* (weekly care planning meetings) are a constant feature and were extended to the Hospice at Home service as the Allied Health Professional disciplines participation on the team increased.

Staff have been encouraged to undertake the European Certificate in Essential Palliative Care for Doctors and Nurses and the Certificate in Essential Palliative Care for Allied Health Professionals. The 3-day Advanced Communication in End of Life Care course is also multi-disciplinary.

[4] www.e-life.ie

Recommendation 25 Increase the educational and support systems to be targeted at GPs, primary care teams, staff in acute hospitals, day hospitals etc. to increase awareness of Palliative Medicine.

Outcome There is a GP Education Forum held in MCC annually. GP trainees are included in the NCHD assignments to MCC. Medical staff from MCC lecture in the Graduate Entry Medical School, UL. Medical staff participate in case conferences, Grand Rounds and intern tutorials at the MWRH. Medical students, student nurses and allied healthcare professionals all participate in pre-arranged student placement programmes in MCC. The Hospice at Home team have taken up the remit of the provision of Level 1 education in the Community as from 2011.

Recommendation 26 Develop working relationships with Universities in the area further.

Outcome A Memorandum of Agreement has been signed with UL regarding co-operative working and student placements. Both parties are collaborating as stakeholders in the All-Ireland Institute for Hospice and Palliative Care and are developing joint proposals for initiatives under its umbrella. Staff from MCC provide lectures on under- and post-graduate courses and staff from UL provide support to MCC programmes.

MCC looks forward to greater linkage with the UL School of Medicine, the RCPI and ICGP, all of whom push out the boundaries for palliative medicine in training and research. Other ongoing research interests at MCC include studies associated with delirium, paediatric palliative care, health promoting palliative care and palliative care for patients with non-malignant diseases.

Extensive liaison and collaboration is being developed with the UL School of Medicine. Medical students from Year 3 and Year 4 rotate through the Hospice In-patient unit.

A particular initiative that marks an innovative step in service development is a Health Promoting Palliative Care project being undertaken with UL. This is a very worthwhile initiative that brings the expertise of Milford Care Centre to the wider community through a structured Compassionate Communities project that asks society to engage with matters associated with death, dying, loss and care.

As an ongoing exercise in an ever changing medical training and research environment, it is necessary to establish a consultation process to identify potential areas of interest and to formalise working relationships. The need for the development of palliative care training modules in under- and post-graduate training schemes will be a continuing challenge.

Medical staff should be fully involved in caring, teaching and researching. In so doing, they also support other health care professionals.

Recommendation 27 Review recommendations from the national needs assessment for paediatric palliative care.

Outcome The Report, A Palliative Care Needs Assessment for Children (DoHC/IHF 2005), "aimed to identify the number of children in Ireland living with and dying from life-limiting conditions and to identify their needs" (DoHC 2005:10). It identified the key principles that should inform future development of paediatric palliative care services.

This led to the publication of *Palliative Care for Children with Life-Limiting Conditions in Ireland – A National Policy* (DoHC 2009). Based on this policy document a comprehensive service plan for palliative care needs of children has been formulated arising from which discussions are ongoing between the MWRH and MCC regarding the implementation the Policy's recommendations. A strong relationship has been developed between the Department of Paediatrics in the MWRH and MCC with specialist palliative care being available to support the care of children, as appropriate and as resources permit.

Recommendation 28 Palliative Care services in the Mid West should participate in the preparation of National Minimum Data Sets for Palliative Care in Ireland.

Outcome MCC was one of a number of pilot sites for testing the Minimum Data Set in 2004. MCC collates data collection for submission to the HSE in accordance with agreed templates. Internally much work has been done to meet the requirements of the National Minimum Data Set and the software package has been upgraded to provide additional statistical information. MCC has a representative on the National Minimum Data Set Working Group established in 2009 to further enhance the original data set and agree definitions. Much more detailed information is being supplied to the HSE on the in-patient, day care and community based services. Work has commenced on the introduction of enhanced statistical information for the acute services and the support bed element remains to be addressed.

Information and statistics should be comparable across service providers and geographical areas in the interest of epidemiology, research and the on-going management of services.

Recommendation 29 Formalise existing ad hoc arrangements between anaesthesia and adult psychiatry.

Outcome Formalising the existing ad hoc arrangements both in the areas of pain management/anaesthesia and adult psychiatry will enhance the quality and breadth of service offered to patients. Regular education meetings with the Pain Service have commenced and discussions around regular joint Palliative and Pain Medicine rounds have begun.

Recommendation 30 Further development of Palliative Day Care Services on a regional basis.

Outcome A Regional Day Services Co-ordinator was appointed in 2010 to identify existing Day Care Centres for Older Persons that might facilitate local

admission of patients with palliative care needs. A directory has been published and support and training needs will be identified and made available as resources permit.

Recommendation 31 Improvements in information technology and telecommunications need to be developed to aid in the co-ordination of services between service providers.

Outcome A Project Officer was appointed in 2010 to develop the *iCare* software application to enhance communication between service elements and facilitate the collation and analysis of statistical information. This will result in a more efficient synchronization of services and more effective communication systems which facilitate the patient to move effortlessly between services.

The Specialist In-patient Unit is able to access X-ray and laboratory reports via a dedicated link with the MWRH systems.

The Clinical Nurse Specialists in MCC's outlying bases have ICT access to its servers although the broadband connection between them needs to be improved.

Recommendation 32 Appoint a fourth Consultant in Palliative Medicine with the appropriate support of NCHDs and administrative officers.

Outcome The case for a fourth Consultant post is based on the criteria set out in the Report of the National Task Force on Medical Staffing [Hanly Report] (DoHC 2003) which recommended one post per 87,000 of the population. Such a post will be required to provide a consultant led service in the Acute Hospitals, Community and the Specialist In-patient Unit.

The key steps involved include developing a job description for the post, the delineation of sessional commitments, negotiating and securing funding from the HSE/DoHC, also securing approval from HSE Central Consultants Applications Unit.

Recommendation 33 Creation of a Chair of Palliative Medicine with appropriate support from NCHDs and administrative support

Outcome The development of the Medical School at UL will enhance the prospects of creating a Chair of Palliative Medicine which will progressively lead to the dissemination of the palliative care ethos. This appointment will be considered in the context of the fourth consultant post being approved and will require further discussion with UL in due course. Other associated actions would include securing the necessary funding from HSE and securing post approval from HSE Central Consultants Applications Unit.

Recommendation 34 Ensure further needs assessment is completed within five years time to review the Palliative Care services in light of previous service developments and their effect.

Outcome A Working Party which reports to the Regional Committees should be established. Its work will include a review of demographics, the impact of the

community and in-patient services to date, the expansion of existing services and the required responses to emerging needs, also the quantification and cost levels of service developments required. Such a review is desirable in the face of changing demographic profiles, raising expectations, new standards, and the incidence of non-malignant conditions requiring palliative care in appropriate settings.

3.0 REVIEW OF RECENT REPORTS ON PALLIATIVE CARE

Over recent years, 'a significant number of reports, strategies, policy documents and plans have been prepared which have implications for the development of palliative care services' (HSE 2009:5). While the learning process is cumulative, it is considered appropriate to review the following four documents because of their particular relevance to this Review.

3.1 Palliative Care Services - Strategic Plan for Specialist Palliative Care HSE West 2009-2013 (HSE West 2008)

This Plan was prepared to give 'strategic direction to HSE West in its development of a comprehensive range of high quality palliative care services in line with evidence-based practices and population health needs assessment' (HSE West 2008:1). It was primarily guided by the NAC Report 2001 in recommending a consultant-led service with multi-disciplinary specialist palliative care teams. It specified specialist palliative care teams as including in-patient and out-patient facilities, day care/therapy, community and acute care, and education, research and bereavement services.

The Plan set out the overall aim for palliative care in HSE West as follows:

> 'HSE West aims to provide an adequately resourced, safe, high quality palliative care service, available in all care settings, that is patient centred, accessible, responsive and equitable, operating in line with evidence-based practice'.

The following objectives were identified:

- Improve access to palliative care services
- Enhance partnerships at all levels to maximise the development and scope of available palliative care services
- Integrate the palliative approach into all clinical practice
- Improve psychosocial palliative care provided to service users, their families and staff
- Increase levels of palliative care knowledge
- Manage risk and continuously improve quality
- Ensure accountability and financial stability.

As part of a very comprehensive implementation plan, it was proposed to increase Consultant Medical posts from 7 in 2007 to 10 in 2013. An increase in bed capacity was envisaged from 58 in 2007 to 92 in 2013.

The main thrust of the Plan was to set out basic criteria for the orderly development of services in the HSE West administrative area.

3.2 Palliative Care Services – A Five Year/Medium Term Development Framework (HSE 2009)

The objective of this document was to develop the palliative care services nationally using a holistic, system-wide approach to addressing the needs identified in the earlier assessment of needs studies. It is grounded in the NAC Report of 2001. It sets out

the required actions and initiatives necessary to address the identified gaps in palliative care service provision.

The document listed 41 national priorities which emerged from the work of a project steering group following its analysis of the various assessments of needs. Those needs were grouped under the following four service categories (HSE 2009:10):

- Priorities relating to Home Care Deficits (12) (Revenue - €10.74m)
- Priorities relating to Specialist In-Patient Bed Deficits (6) (Revenue - €6.956m)
- Priorities relating to Capital Developments (15) (Capital - €237.34m and Revenue - €48.02m).
- Priorities relating to Acute Hospital Support (8) (Revenue - €6.035m)

The capital and revenue requirements to deliver on the 41 national actions were estimated to cost combined €308.825m, i.e. capital of €237.34m and revenue of €71.485m.

Similar to the HSE West Plan 2009-2013 (HSE West 2008), the main thrust of the Framework Plan was to set out basic criteria for the orderly development of services throughout the State.

3.3 Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks (HSE/IHF 2008)

This study developed from the view that 'Irish health care policy has recognised that many people with life-limiting diseases should have their palliative care needs met without a referral to SPC [specialist palliative care]' (HSE/IHF 2008:2). Life-limiting conditions such as COPD, dementia and heart failure exhibit palliative care needs that are at least equal to those who have a cancer diagnosis as well as having other co-morbidities. Services in other countries have developed around 'the need for palliative care to be part of the overall management of the patient's disease' (HSE/IHF 2008:2). In Ireland, there are few instances 'of national palliative care being delivered within disease-specific services' (HSE/IHF 2008:2).

Estimates from palliative care reports suggest 'that the inclusion of people with non-malignant diseases within the SPC services would increase the demand for the service by 80% … that the desired level of activity within SPC for these patients would be 25% (HSE/IHF 2008:3). Access to specialist palliative care services to date for persons with life limiting diseases is limited, the main reasons being inadequate eligibility, lack of resources and the fear of being overwhelmed by the potential numbers involved. The Report favours a phased approach to the provision of a more integrated service and feels that the operational management of such as service is all-important. It also states that 'much of this high quality care should be provided within existing and developing disease management programmes, with SPC responding where needs become complex and extraordinary' (HSE/IHF 2008:4). It emphasises the point that, 'positive relationships between a wide range of organisations, professionals, patients and carers' (HSE/IHF 2008:4) is required, which will only come about 'where people can see that through collaboration high quality care can be provided for all people who have life-limiting disease, whatever their diagnosis' (HSE/IHF 2008:4).

The Report recommends that 'governance and monitoring systems be introduced to ensure that specialist palliative care is provided on the basis of need rather than diagnosis to all patients with life-limiting illness' (HSE/IHF 2008:52). It finds 'that persons with non-malignant diseases benefit most when palliative care service models are based on a collaborative and/or shared care approach between the disease specific specialist primary care staff and the specialists in palliative care' (HSE/IHF 2008:53). There is need for an educational response to the emerging challenges implicit in an integrated service. These range from 'formal education provision' [to] 'informal opportunities' (HSE/IHF 2008:52) in meeting the changing nature of palliative care needs.

It is of the nature of services to respond to the differing needs of patients as they emerge, a view recognised and supported by the Report. The same approach must apply to those with life-limiting non-malignant illnesses. Research is required to plan and respond to those needs. Such research will range from mapping patient locations to the most appropriately structured clinical and support responses required for those with COPD, dementia and heart failure. Palliative care can be embedded in the care pathways at the different levels of care.

3.4 Palliative Care for Children with Life Limiting Conditions in Ireland – A National Policy (DoHC 2009)

As the Report sets out, 'children's palliative care has evolved from the specialty of paediatrics rather than adult palliative care and is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancing the quality of life for the child and providing support for the family, and includes the management of distressing symptoms, provision of respite and care through death and bereavement. … Adolescents requiring palliative care have their own unique needs' 2009: vii)'. 'A life-limiting condition is defined as any illness in a child where there is no reasonable hope of cure and from which a child or young adult will die' (DoHC 2009: vii). Children with these conditions are likely to have palliative care needs' (DoHC 2009: vii). The Policy also states that 'there are approximately 1400 children living with a life-limiting condition in Ireland and in the region of 490 childhood deaths per year. Of childhood deaths due to life-limiting conditions, the majority occur in the first year of life, with approximately 350 deaths per year from life-limiting conditions' (DoHC 2009: vii). A Palliative Care Needs Assessment for Children was carried out in 2005.

A responsive palliative care service for children and their families needs to function within a co-operative model with close liaison between general practitioners, paediatricians, nursing services, therapists and the voluntary sector. This Policy recommended that there should be a hospital-based specialist palliative care team led by a Consultant Paediatrician with a Special Interest in Palliative Care and, in the Dublin area, would be based in the proposed new paediatric hospital. For children outside of the Dublin area, the Consultant Paediatrician with a Special Interest in Palliative Care would liaise with locally based nursing posts, therapy posts, Hospice-in-the Home and respite care (both in the home and away from home) which would support the primary care services. Whereas palliative care for adults usually follows a 'predictable disease trajectory and prognosis, the needs of children with life-limiting conditions differ significantly from those of adults. There is an overlap between some

of the needs of children with life-limiting illnesses and the care that children with disabilities will require. Not all children with palliative care needs will require specialist palliative care input' (DoHC 2009:2).

The Policy accepts the idea of a Hospice-in-the-Home service for children in need of palliative care. Such children and their families should have access to nursing, care assistants and home help as required, also respite care, on a 24-hour basis. They should also have access to therapy services at both primary and hospital care levels. The Policy sees outreach nurses having a particular role in facilitating integration of service delivery and should be the link between the primary care teams and the hospital network system. In all of this, the parents, for whom these times can be very distressing, must be actively involved.

Acute and maternity hospitals should provide an appropriate environment for children with palliative care needs. The provision of beds and other appropriate resources, including respite facilities, should be developed. The Consultant Paediatrician with a Special Interest in Palliative Care should provide the necessary advice and support to the consultants and other health professionals in the acute and maternity hospitals. Education and play should also feature in a palliative care service where the young person is growing and developing physically, emotionally and cognitively. Bereavement care must also be a central component for the children, their parents and families.

The Policy sees the HSE and voluntary agencies developing closer relationships as they provide services for children with life-limiting conditions. These arrangements should be grounded in Service Arrangements between the HSE and voluntary agencies where the autonomy of the voluntary agencies would be recognised and respected and the need for evaluation and review of services is accepted as routine.

4.0 DISCUSSION AND ISSUES FOR THE FUTURE

4.1 Capital and Revenue Expenditure 2004-2010

The development of the range of in-patient and community services is reflected in the expenditure patterns as set out in Appendix 3.

The present direct HSE revenue allocation to MCC services is €11.089m., (2010 allocation), net of the cost of medical and pharmacy personnel directly employed by the HSE. The HSE is the main source of revenue funding for ongoing services. Capital funding has also been made available for previous projects on an agreed basis. Through a Service Arrangement, the HSE funds approximately 80% of ongoing costs with the balance being met by MCC from other sources.

Included in the HSE Service Plan for 2010 was a reference to commissioning the new development service areas. In December 2010 a funding arrangement was agreed between MCC and HSE covering a five-year period whereby both agencies would contribute to the costs of the new services on a sliding scale basis. (see Table below)

	2010 €	**2011 €**	**2012 €**	**2013 €**	**2014 €**
HSE Funding	**80,,000**	**620,000**	**940,000**	**1,260,000**	**1,503,000**
MCC Funding	**80,,000**	**1,260,000**	**940,000**	**620,000**	**377,000**
Total Funding required	**160,000**	**1,880,000**	**1,880,000**	**1,880,000**	**1,880,000**

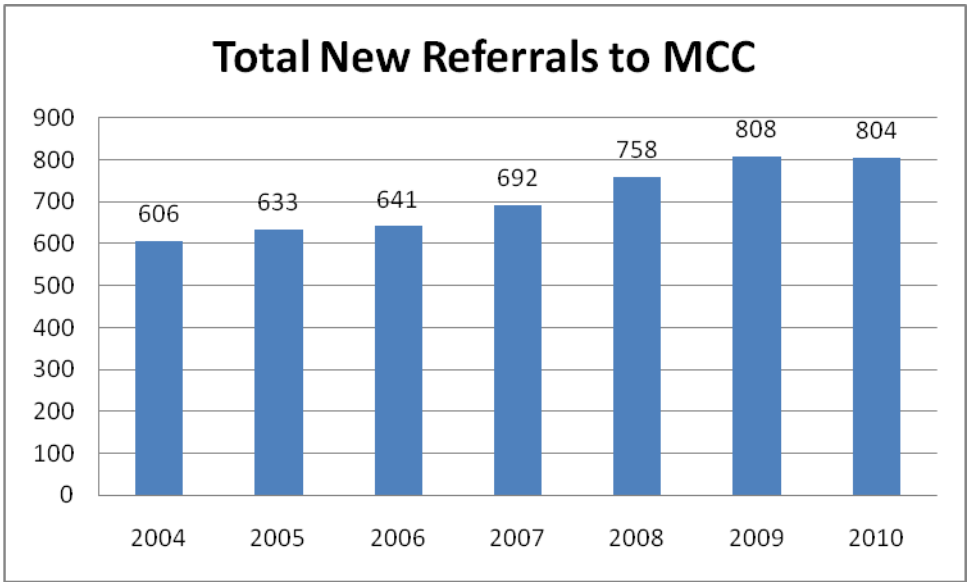
At the end of the period the HSE will be funding 80% of the costs.

Any future development proposals will be on foot of priorities set out in the HSE's 5 Year Framework Report 2009-2011 (HSE 2008).

4.2 Activities

Figures for activity levels under the various headings are set out in Appendix 4.

There were 4,942 individuals referred to Milford Care Centre's Palliative Care Service between 2004 and 2010. Many of the patients would have been referred to a number of service elements, e.g. the Specialist In-patient Unit and Hospice at Home.



The newly built unit at MCC, when fully operational, will add substantially to the range of services, with a major focus on supporting community services. With a third Consultant in Palliative Medicine and additional supporting clinical staff, it will augment and expand present community services through the development of Out Patient Clinics, Assessment Units and expanded Day Care services. The expanding educational function, and its association with UL, will also contribute to increasing standards, expanded research opportunities together with a greater profile for medical and other training opportunities (at specialist and intermediate levels), thus opening up the possibility of distance learning programmes and provision of extra student placements.

4.3 Cancer Projections

The National Cancer Registry sets out projections for increases in the incidence of cancers over the period 2005-2035. These are set out in Appendix 6. These projections present challenges to providers of services, to health care professionals and to the government and public in how the extra services are provided and on how they are funded. The HSE, in conjunction with MCC, should consider the most appropriate response whether by extending community services or extending the in-patient unit.

4.4 Reconfiguration of Acute Hospital Services

The Mid-West Reconfiguration Group is concerned with Acute Hospital Services but has not fully considered the role, place or function of Palliative Medicine to date. Because of the relatively well developed Palliative Care service in the Mid-West Region, it did not feature as a priority in the National Cancer Control Programme[5]. The implications of this reconfiguration on the acute hospitals of the region, and on the palliative care in-patient services in particular, are not yet clear.

The future plan for acute services in the Mid-West Region is still under active consideration. The question of how those services interface/merge with palliative medicine remains to be developed. Such decisions will also impact on the duties and

[5] The National Cancer Control Programme was established in 2007.

workload of the palliative care Clinical Nurse Specialists (CNSs) in all of the acute hospitals.

The short and long-term implications of the foregoing developments should be examined and addressed as soon as possible. Current and future configuration issues, as they relate to St. John's, Ennis and Nenagh General Hospitals, in conjunction with the MWRH, will influence the outcome of those developments.

It must be noted that due to insufficient Palliative Medical Consultant cover, there has been no direct Palliative Care Medical input to St. John's, Ennis and Nenagh Hospitals. Telephone support and advice is available from the Consultants and Medical Team based at MCC. The third Consultant will provide direct sessional input into St. John's Hospital.

The major commitment of the Consultants in Palliative Medicine to the Acute hospitals in the region will be to the MWRH with liaison and other service commitments to the smaller hospitals.

The third Consultant in Palliative Medicine will support both the in-patient and community services provided by MCC as well as provide greater linkage with the acute services of the HSE. It will also allow for development of an OPD service in Milford Care Centre and facilitate further developments in the specialist community team and liaison with the UL Medical School.

4.5 Hospice at Home Evaluation

The results of the ongoing evaluation being carried out by UL are awaited. It is clear that this service is impacting in a significant matter on patients' preference to remain and be cared for in their own homes for as long as possible. It will further develop with the third Consultant's input to the Hospice at Home Scheme.

4.6 Education, Research and Professional Development

Nationally, education and research in Palliative Care is entering into an exciting time of development and opportunity with the establishment of the All Ireland Institute for Hospice and Palliative Care. The Institute will have a key role in the development, commissioning and evaluation of education and research programmes in Ireland and Milford Care Centre, as a member of the consortium managing the Institute; will engage proactively in its work, maximising opportunities for collaboration and development that arise. The Education Service aims to continue its national role as Co-ordinating Centre for the European Certificate in Essential Palliative Care and to drive Ireland's first evidence based programme in Advanced Communication Skills in Palliative Care for Qualified Healthcare Professionals.

Milford Care Centre has recognised the need to gain quality assurance via FETAC as the first step within which to focus on the development of skills education for all staff, regardless of discipline and will continue to expand the range of innovative and accessible education programmes offered.

The momentum toward the development and implementation of health promoting palliative care will also expand education service delivery to meet the needs of the

general public and focus on raising awareness around the broader issues associated with death, dying, loss and care.

Research activity and outputs from Milford Care Centre have increased significantly in recent years across all disciplines. The focus on research will continue to develop through the appointment of a research and evaluation co-ordinator to support and facilitate staff who undertake research projects. The strategic link with University of Limerick is also a key support for the further development of research capacity.

While considerable developments have occurred in addressing the educational needs of medical nursing and allied health care professionals working in specialist areas particular attention should be had to ensure that the needs of staff working at Level one and Level two service provision are addressed. The Education and Hospice at Home services are developing specific education programmes for staff working in Older Persons' residential and day care settings and in primary care teams.

4.7 Staffing the Service

Manpower planning has been, and will continue to be, a key requirement in terms of successful implementation of the principles of palliative care service delivery. Hence the emphasis on education, research and professional development, skill mix, multi-disciplinary team working and benchmarking against best practice at national and international level.

Milford Care Centre has been fortunate in being able to source quality staff of the highest calibre. It is confident that by planning for the Human Resource needs of the organisation, it will continue to employ the right quantity of staff with the necessary skills and knowledge for effective functioning. The current labour market is characterised by large numbers of relatively well-trained people who are actively seeking employment. Following successful recruitment of the right staff, Milford will develop a range of procedures and practices that facilitate the retention of those staff that are recruited, such as performance management review, facilitating continuous improvement, designing effective systems of work and managing the employment relationship.

4.8 Standards

There are continuing challenges to be met in providing a service to the highest standards which continuously aims to address existing and emerging needs. There is need to benchmark against 'best practice' elsewhere, nationally and internationally, and to develop measures that assist in evaluating, reviewing and planning services. All services must be developed consistent with criteria of efficiency and effectiveness. MCC has taken a most progressive approach in this regard with initiatives in reviews and evaluations of services.

The response to the statutory role of HIQA in publishing standards relating to palliative care and its carrying out of inspections of in-patient units and community services should be given very high priority. MCC has taken some very innovative steps in this regard. These include the continually developing contacts with UL in relation to medical and other health professional training, ongoing research and evaluation projects and the membership of the All Ireland Institute for Hospice and

Palliative Care. Participation in the Hospice Friendly Hospitals Initiative also introduces the services to wider perspectives. Apart from the formal academic contacts, there is further scope to explore educational opportunities for health care professionals and support staffs across all disciplines. All of those prepare MCC's services to meet the robust standards expected to be set by HIQA in its licensing scheme.

4.9 Health Service Reorganisation

The emerging HSE Primary Care teams are facilitating the shift of focus of care for patients with advanced progressive disease from acute settings to primary care, thereby reducing unnecessary admissions and length of stay in acute care. These teams are also seeking to establish closer integration with community based specialist palliative care.

The reconfiguration of Acute Hospital Services in the Mid West region, combined with the Integrated Service Area concept will further enhance collaboration between the various service elements.

The Directorate of Clinical Strategy and Programmes and Directorate of Quality Risk and Clinical Care have been established within the HSE. Their role is to strengthen clinical leadership, improve clinical performance, and ensure care is delivered in a manner that maximizes quality while minimising expenditure and providing the change leadership required to:

- Develop national treatment guidelines, standard operating procedures, (SOPs), care pathways, decision support algorithms, and performance metrics
- Support local implementation of best practice and correction of underperformance
- Provide a sustained focus in improvement in quality and resource utilisation in the medium to long term
- Identify and implement innovations that will deliver measurable improvements in access, quality, and resource utilization within the short term
- Provide effective communication to stakeholders within and outside the HSE
- Support the design and implementation of a transparent resource allocation model.

4.10 Future Developments/Additional Services

The Specialist Palliative Care Service in the Mid West constitutes a well integrated service and few people fall through 'the cracks.' How far should the palliative care service be extended? Issues such as that of sustainability will always arise. Ongoing development of appropriate community support services should be a priority. These include those services delivered by health care professionals and enabling communities to develop coping strategies in the area of death, dying, loss and care.

As discussed at Chapter 3 above, questions concerning the provision of services by MCC to embrace new directions will have to be considered.

The Report entitled Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks (HSE/IHF 2008) [Extending Access Study] suggests that patients with life-limiting conditions such as COPD, dementia and heart failure

exhibit palliative care needs that are at least equal to those who have a cancer diagnosis as well as having other co-morbidities. Where and by whom should such services be provided? With its proven record of providing for those with a cancer diagnosis and a growing number of non-malignant cases, MCC has the necessary skills to contemplate this area of need, subject to successful definition of a service and the resources required both at in-patient and community levels.

The Report of the Working Party entitled *Palliative Care for Children with Life Limiting Conditions* (DoHC 2010) raises concerns on how to develop linkages between local and national paediatric services, the primary care teams and the specialist providers of services in the provision of services to children with conditions that are likely to have palliative care needs. It appears that this can be best achieved at community level via the Hospice at Home teams who have the skills and knowledge for this purpose. The developing model of care for patients with life limiting disease in the community will be enabled by formalising supports and structures for staff in the delivery of palliative care.

4.11 Statutory/Voluntary Partnership

The long-standing partnership approach adopted by the Mid Western Health Board, (and subsequently the HSE) and Milford Care Centre has stood the test of time. Their collaboration with UL, initiated in 1990 and strengthened further during the last five years, has facilitated linkages with the academic community and will continue to bear fruit through the All Ireland Institute for Hospice and Palliative Care initiatives and academic inputs.

The role of MCC as the Mid West Region's specialist palliative care provider has been clarified and the annual Service Arrangement will safeguard the interests of both parties.

Links between MCC and other voluntary agencies are likely to expand further in the future as opportunities arise.

4.12 General

Early intervention and better communication between the various teams and individuals, with greater use of information technology will lead to better and more effective streamlined services. Patient-held records (patient passports) should be a way forward in conjunction with families and the care professionals involved.

With projected increases in the incidence and prevalence of cancers, better treatments and earlier detections, cancer patients will be more chronically ill than acutely ill. More remissions will lead to more long-term care. There will be pressure to care for those with non-malignant conditions in their own homes such as children with life-limiting conditions. Facilities for respite care, including continuous assessment and full medical team involvement, should be expected in the future. Patients will attend locally based day care services, e.g. in Thurles, Ennis, Newcastle West, to be seen by the members of the multi-disciplinary teams. Provision of transport will be a pressing issue. The role and function of the volunteer must be recognised and better defined as this function can be provided by such a group provided they are adequately trained and supported. Lessons can be learned from the experiences of the UK children's

hospices. A regional approach involving satellite centres around a main hub will bring services nearer to patients' homes thus affording easier access by them and their families. Indeed, as palliative care interests look forward, an exploration of more effective approaches will be uppermost in everybody's minds.

There has been insufficient research on palliative care in Ireland. With the emergence of the All Ireland Institute for Hospice and Palliative Care, there is an opportunity to remedy this deficiency with collaborative approaches between all hospices and related community services. The sharing of information, the preparation of standard operating procedures and arms length comparisons of different experiences will lead to more efficient, effective and responsive services.

5.0 CONCLUSIONS

5.1 The **partnership approach**, espoused as an ideal system for service delivery, has found ready expression in the Mid-West Region where the HSE and MCC have found common cause. There has been a meeting of minds between those managers of the HSE and colleagues in MCC in devising a system which has delivered a first-class service. As one views the MCC services, one has to be impressed by the well integrated and developed system of palliative care. The range of services provided compares very well with those across the country and indeed abroad. The Little Company of Mary had the foresight to establish a service in the 1970s/1980s when funds were scarce and when competing needs had to be also taken into account. Their responses to a pressing need have grown and flourished over the years.

In conjunction with local HSE, the Chief Executive and Board of MCC have been assiduous in ensuring the development of services to such a high standard. The importance of advocating, influencing and networking with the DoHC, HSE, politicians, other voluntary organisations and stakeholders must also be recognised. It is a challenging role that may not be always be well understood. Indeed, the Mid West is clearly an area where public/voluntary partnerships have evolved in a progressive and innovative manner, the result of which has greatly benefited palliative care service recipients throughout the Region.

5.2 While the relevant Consultants at MWRH have no direct involvement with MCC, they have regular contacts with the Consultants in Palliative Medicine who work there. They assert that the palliative care function, based on the in-patient unit at MCC and supported by associated community services, works very well. They consider that the services are up there with the best in these islands. Indeed, there is an excellent service given there by the consultants in palliative medicine, their medical support staff, the nurses, the various therapists and support staff involved where the welfare of the patient is always placed first. The system works well for patients and appropriate treatment is administered with the palliative care dimension introduced and fully explained from the beginning. There are very few problems being experienced.

The quality of services provided by MCC, as the lead provider, is very high. The services have earned a very high reputation because of what they do. The old image of the 'hospice' does not prevail there. Medical, nursing, and therapy standards are continuously under review with a learning and research focus always present. In addition, the ethos/philosophy of care, and the Mission Statement underpinning the provision of services at Milford, helps to ensure that the highest standards of care are in place and aimed for at all times.

5.3 While much has been achieved over the years, there is also the challenge in these difficult financial times of safeguarding current service levels and standards. Equally, the need to pursue further development of services, in a planned strategic manner, and through the statutory/voluntary partnership basis, must be recognised. Being no different to any other categories of patient, the needs of palliative care patients continue to change. There is also the added challenge of implementing the Extending Access Report and the Paediatric Palliative Care Report in the Mid West.

5.4 The MCC service is highly regarded for the service it provides and for its vision of providing a comprehensive community service. It 'punches above its weight'; it is highly functional, well organised, effectively delivered and responsively integrated with other mainstream services. It has a very high level of expertise which will be further enhanced with the appointment of the third Consultant in Palliative Medicine. The population of the Mid West may be reassured with the quality of service being provided, its flexible responses to needs and the working relationships developed over the years.

MCC has clearly anticipated the need to develop an integrated in-patient and community based service. While priority in the past was given to malignant conditions, there is need and scope to develop responses for non-malignant conditions, e.g. end stage conditions, but not excluding cancer care. Thus linkage can be made with other service providers and their health professionals to offer help as required in both advisory and direct capacities.

5.5 MCC services are seen as 'visionary' with their regular reviews of values and processes. The WHO concept of 'social accountability' is implicit in the policy documents with the emphasis on review and evaluation of services. MCC has positioned itself as being answerable for the palliative care needs of the region with the patient being seen as centre stage. It has managed to successfully address the needs of a patient population using an evidence based approach. From this background has emerged a service based on best practice in Ireland and indeed beyond. The clinical and support staffs of MCC have developed an expert understanding of palliative care. They are able to engage locally and nationally to ensure that MCC is at the cutting edge of palliative care provision. A comprehensive service has been developed around an in-patient unit, care in the home, day care and educational elements. As the Hospice at Home service allows the community to have its patients live and be treated at home as long as possible, such is seen as a very responsive approach. Linkages into the community are truly pioneering and are valued. As a 'high achiever', Milford is a model for other areas especially with its emphasis on education and research collaboration, both in Ireland and abroad.

5.6 The MCC palliative care service leads the country in terms of being open and transparent. It is developing a significant role for volunteers in the service, thus creating a vibrant network that has enhanced the positive and non-threatening message about palliative care. MCC has engaged with its stakeholders through fundraising and marketing of its services. Being in the public eye, there is a very high awareness of its services within the community. Clearly, the voluntary/statutory partnership which MCC operate with the HSE works well and is a credit to all concerned. The HSE has been solid in its support.

Appendix 1

LIST OF PERSONS INTERVIEWED

Ms. Teresa Bulfin, Acting Local Health Manager, HSE

Mr. Paul Burke, Consultant Surgeon, MWRH

Dr. Marian Conroy, Consultant in Palliative Medicine

Prof. Paul Finucane, Head of Medical School, UL

Mr. Kieran Ginty, Cancer Services Manager, MWRH

Mr. Bernard Gloster, former Local Health Manager, HSE

Mr. Gerry Gorey, Head of Human Resources, MCC

Prof. Rajnish Gupta, Consultant Medical Oncologist

Ms. Catherine Hand, Nurse Manager for Cancer Services, MWRH

Ms. Jacqueline Holmes, Deputy Director of Nursing, MCC

Ms. Joan Kelly, Nursing Services Manager, Irish Cancer Society

Dr. John Loughnane, General Practitioner, Newcastle West

Ms. Marian Moriarty, Director of Nursing, MCC

Ms. Carol Murray, Head of Support Services, MCC

Mr. Eugene Murray, Chief Executive Officer, Irish Hospice Foundation

Mr. Pat Quinlan, Chief Executive, MCC

Mr. Jim Rhatigan, Head of Therapy and Social Care, MCC

Ms. Cathy Sheehan, Head of Finance, MCC

Mr. Mark Sparling, General Manager, MWRH

Dr. James Stodart, Locum Consultant in Palliative Medicine

Prof. Mary O'Sullivan, Dean of Education and Health Sciences, UL

Appendix 2

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Appendix 3

DEVELOPMENT FUNDS 2004 – 2010

The tables below identify the Capital, Revenue and WTE requirements and allocations associated with the *Seven Year Plan*.

Table1: Revenue Funding and WTEs

Service Element	Revenue Funding		WTE	
	Requirement per Strategy	*HSE Approved	Required per Strategy	*HSE Approved
	€	€		
Specialist In-patient Unit	2,543,150	1,922,493	53.3	24.7
Community Services	4,930,310	2,033,887	64.25	31.5
Specialist Day Care	868,530	647,925	15.6	13
Education & Research	643,455	204,726	10	3.1
Central Supports	1,096,589	356,487	14.5	10
Acute Hospitals	2,242,400	843,875	17	5.5
TOTAL	**12,324,434**	**6,009,393**	**174.65**	**87.8**

*** Incorporating 5 Year Development Plan 2010 – 2014**

The above figures include the palliative care requirements of the HSE Acute Hospitals and Primary, Community and Continuing Care, Community Support Units and Milford Care Centre.

Given demands on global Development Funds within the health sector, combined with the very challenging economic climate the Mid West was very fortunate to achieve a significant increase in its funding base combined with a total of 87.8 posts. In addition to HSE core funding Milford Care Centre's ongoing contribution of 20% towards the costs of service provision has increased on a pro rata basis as the base budget has grown. The support of the people of the Mid-West to the Centre's fundraising activities is very much acknowledged.

Service elements allocated funding include an increase in the number of beds in the Specialist In-patient Unit, expansion of the Day Care and Education, Research and Professional Development services, establishment of a multi-disciplinary Hospice at Home service and appointment of a second Consultant in Palliative Medicine, NCHDs and pharmacy personnel.

Table 2: Capital Funding

Service Element	Funding Required per Strategy	Total Capital Funding Expended	* Total HSE Approved Funding	MCC / Other Approved Funding
	€	€	€	€
Total Region	**5,580,000**	**12,800,000**	**5,300,000**	**7,500,000**

*** Of the €5.3m, Milford Care Centre was allocated €4.5m and the balance of €1.3m was committed to the development at St. Ita's Hospital, Newcastle West.**

The Capital Project element included developments at Milford Care Centre and St. Ita's Hospital, Newcastle West. The costings used were 2004 rates which, in light of the boom in the construction sector, were underestimated. Also, due to the involvement of philanthropic and voluntary organisations during the course of the Strategy, opportunities arose to expand the original concepts. These developments, based on a statutory and voluntary funding partnership agreement have enhanced service provision and the delivery of education programmes.

The Capital Project in MCC was completed during 2009 and the final elements were brought into operation at the end of 2010 in line with the 5-year funding arrangement agreed between the HSE and MCC.

The Capital Project in Newcastle West was also completed in 2009 and the Day Care element is operational on an interim basis. However the 4-bed unit has not opened and discussions continue regarding the required funding.

Appendix 4

SPECIALIST PALLIATIVE CARE STATISTICS

Specialist Palliative Care activity in the Mid West occurs in a number of settings:

- Specialist In-patient Unit
- Hospice at Home (community based services)
- Day Care
- Mid Western Regional Hospital – Out-patients and liaison service

Care is also provided by Primary Care Teams/Networks, General Practitioners, designated beds in Community Support Units (Intermediate or Level Two Care) and in Nursing Homes.

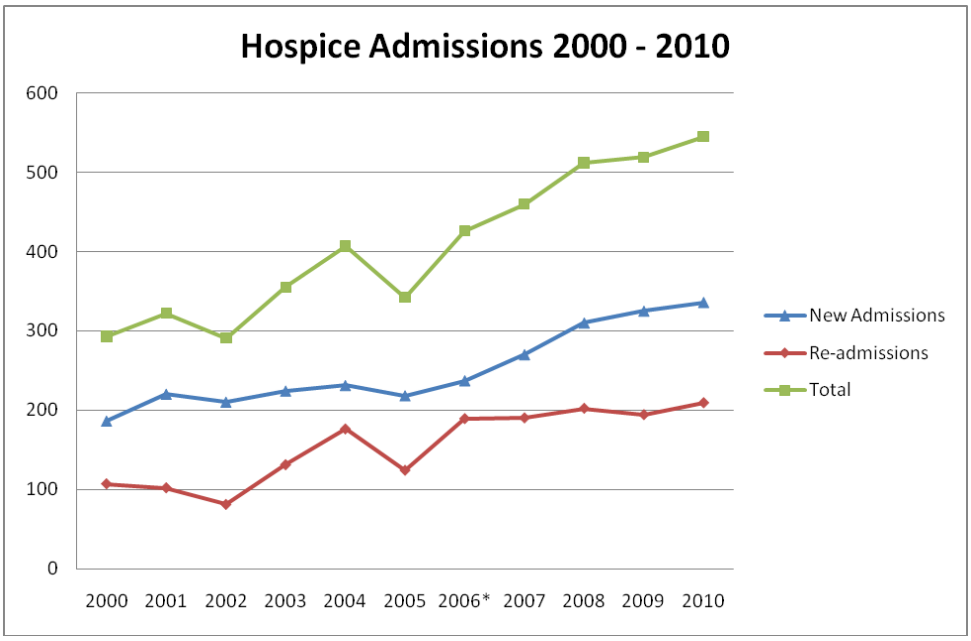
There were 4,942 referrals to Milford Care Centre between 2004 and 2010. The number of patients referred in 2004 was 606 growing to 804 in 2010, an increase of 32.7%.

Specialist In-patient Unit

Total admissions to the Specialist In-patient Unit increased from 293 in 2000 to 545 in 2010, an increase of 86.01%. Bed numbers increased from 20 at the beginning of the decade to 30 in 2006 (opening on a phased basis during that year).

In the period 2000 to 2010 the number of new admissions to the In-patient Unit increased from 186 in 2000 to 336 in 2010, an increase of 80.65%, while the number of re-admissions increased from 107 to 209, an increase of 95.33%.

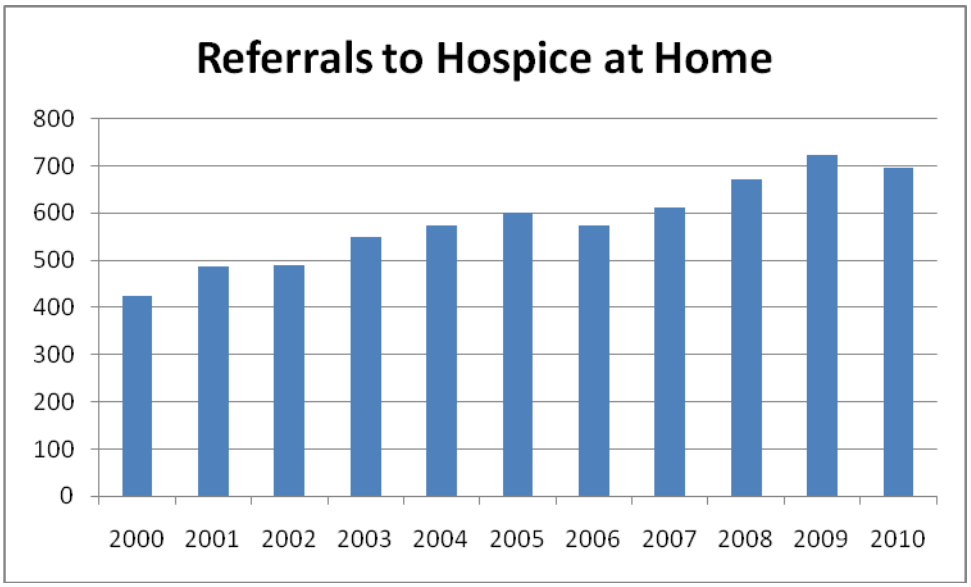
The comparable figures for the period 2004 to 2010 are 45.45% for new admissions and 18.75% for readmissions.



During that period, the average length of stay fell from 18 days in 2000 to 13.63 days in 2010, a decrease of 24.28%. With bed capacity of 20 up to 2006 and 30 thereafter, bed occupancy fell from 73% in 2000 to 71% in 2010.

Hospice at Home

Referrals to the Hospice at Home service increased on a consistent basis from 425 in 2000 to 696 in 2010, an increase of 63.76%. The increase for the period 2004 to 2010 was 21.47%.

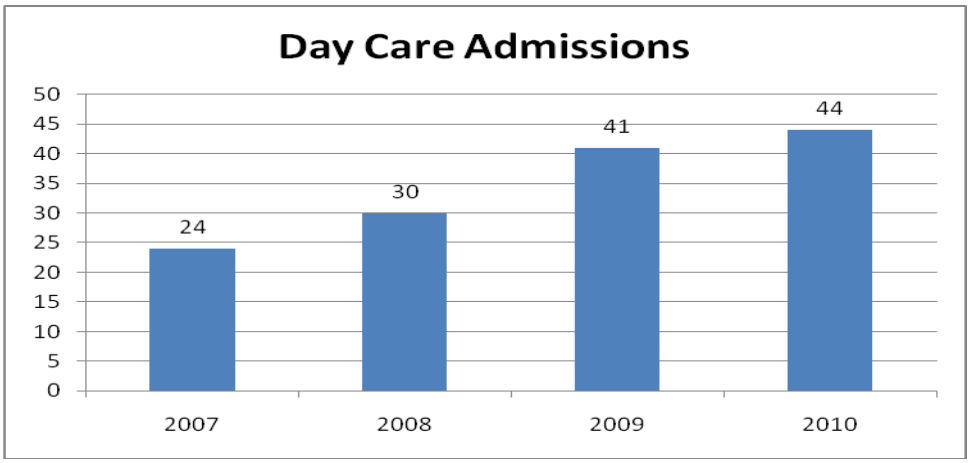


These activity figures indicate a high take-up of service and increasing demand to which it has been possible to respond due to the developing Community Service.

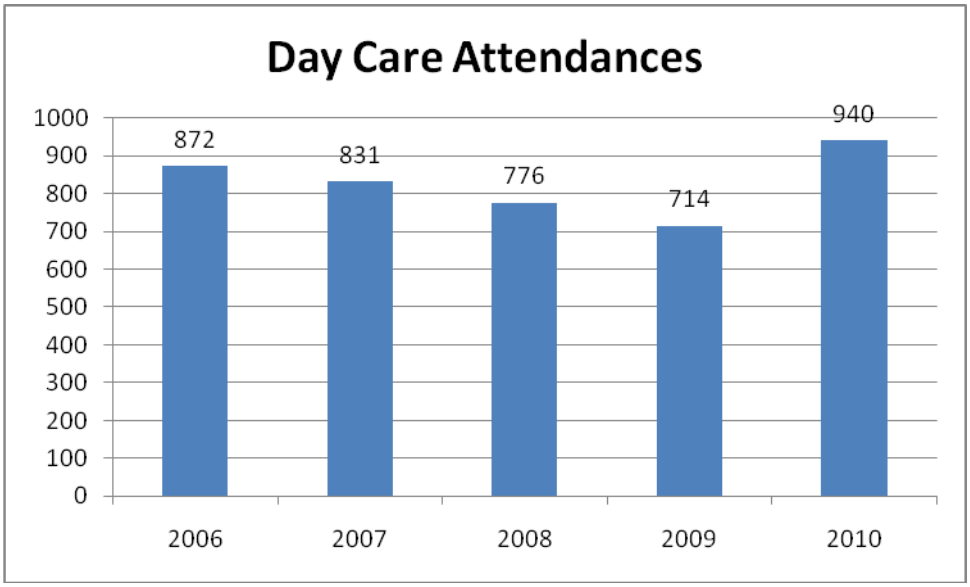
Palliative Day Care

The Day Care Centre operated 2 days per week to the end of December 2010 and will provide services three days a week from January 2011.

The number of admissions to the Day Care Centre increased year on year between 2007 and 2010.

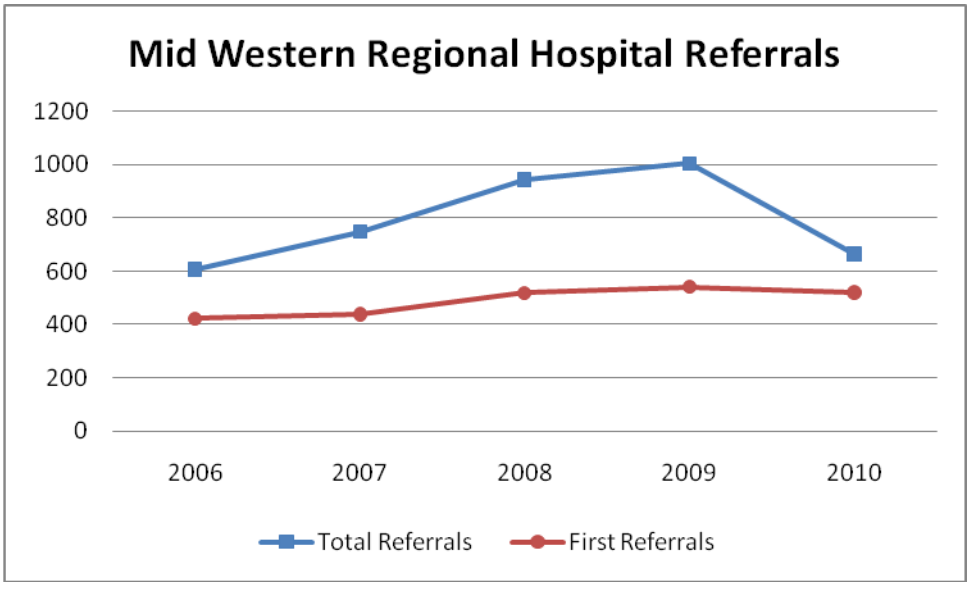


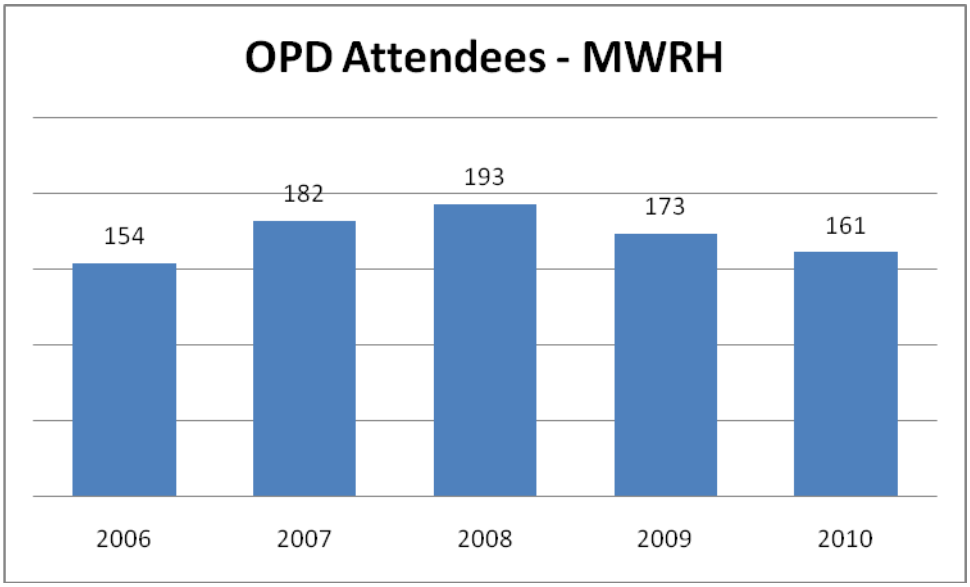
Attendances increased significantly between 2009 and 2010 and a further increase is anticipated for 2011 due to the Centre opening a third day although the impact of the transition from Day Care to Day Hospice during 2011 has not been quantified as yet and will depend on a number of factors including the appointment of the third consultant.



Mid Western Regional Hospital

Referrals in the MWRH have increased on a yearly basis and the Out-patient clinics have also been busy. Although the referrals for 2010 appear to be lower this is due to a change in the way data was collected. The new system is consistent with the criteria in the National Minimum Data Set.




OPD Attendees - MWRH
154
182
193
173
161
2006
2007
2008
2009
2010

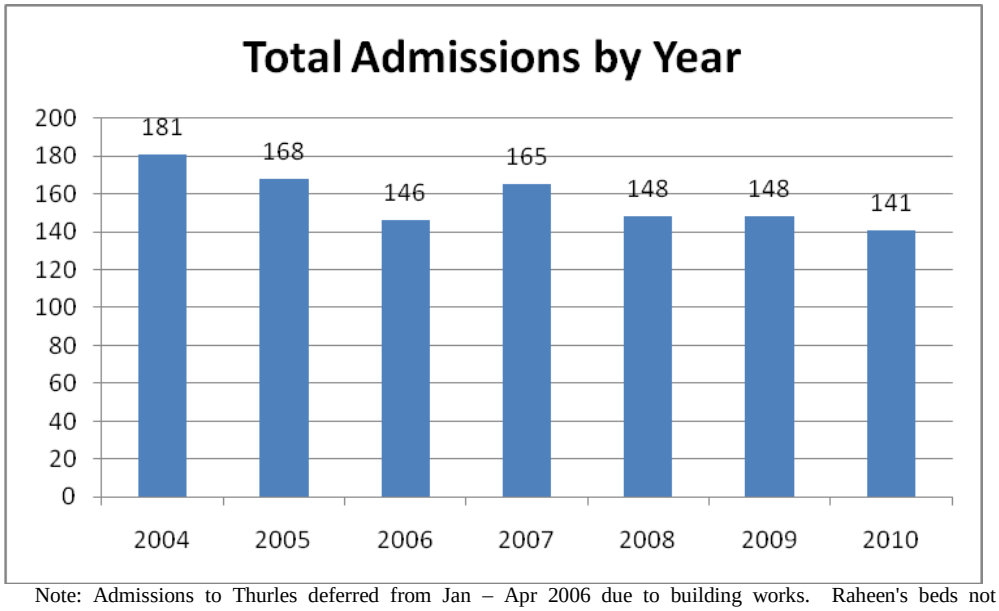
Appendix 5

COMMUNITY SUPPORT UNIT STATISTICS

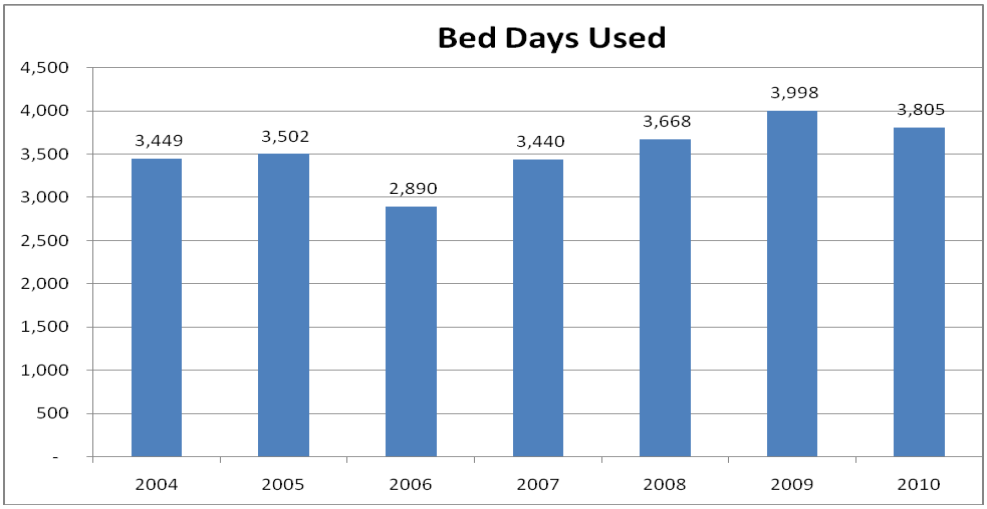
Community Support Units

The beds in the Community Support Units are intended for short-term use by patients with non-complex needs, respite and end of life care. Patients remain under the care of the General Practitioner and the nursing staff in the Units are supported by the local Clinical Nurse Specialists. Many of the staff in the Units have availed of educational programmes in Milford Care Centre and the Educations, Research and Professional Development Service continues to work with them to enhance capacity at local level.

Activity has been steady over the last number of years in terms of admissions although there has been an increase in the number of beds days used. Bed availability at the various units has been reduced from time to time due to building/refurbishment work or staffing shortages.



Note: Admissions to Thurles deferred from Jan – Apr 2006 due to building works. Raheen's beds not fully operational Jan - Jun 2006 due to renovations. Additional two beds opened in Milford from Sept 2007. Beds in Nenagh closed for most of 2010.



Appendix 6

CANCER REGISTRY PROJECTIONS

Projections[6]

The National Cancer Registry projects an annual 6% - 7% increase in the number of invasive cancers to 2035. The following paragraphs are extracts from its *Cancer projections 2005-2035: A Summary.*

'Between 2005 and 2035, the overall number of invasive cancers is projected to increase by 17,063 (165%, 6% annually) for females and by 24,809 (213%, 7% annually) for males (Table S2, Figure S1). If non-melanoma cancer of the skin is excluded, over the same period the number of invasive cancers is projected to increase by 12,479 (168%, 6% annually) for females and by 19139 (232%, 8% annually) for males.

Over the ten-year period 2010 to 2020, the total number of cancers is projected to increase by 40% for women and by just over 50% for men. An increase is expected in the numbers of all common cancer types, ranging from 1% for kidney cancer to 78% for non-melanoma skin cancer in men, and from 6% for stomach cancer to 66% for kidney cancer in women.

Over the period 2010 to 2030 the projected overall increase in numbers is 95% for women and 120% for men (127% excluding non-melanoma skin cancer), with the largest increases being expected in skin cancers (both melanoma and non-melanoma) in men and kidney cancer in women. By 2020-2025, the number of lung cancers in women is projected to exceed the number in men. As noted in the previous report, most of the projected increase is attributable to expected demographic change. Although the size of the national population is projected to increase by 37% between 2010 and 2030, the number aged over 65 (the great majority of cancer patients) is expected to increase by 90% for females and 112% for males (2). This demographic change alone (assuming no change in underlying cancer rates) would increase the number of invasive cancer cases in females by 12,338 and by 19,882 in males between 2005 and 2035 (2008:2).'

'… the number of newly diagnosed cancers is increasing by 6-7% annually and, unless major reversals of trends occur in the near future, the number is likely to double in the next 20 years. The underlying risk of developing cancer is increasing by less than 1% annually and the expected increase in numbers is primarily attributable to the projected rise in our older population (2008:4).'

'The expected effect of demography on cancer numbers is striking, but not specific to cancer. The burden of many diseases is expected to increase dramatically in the next 20 years, with clear consequences for the provision of services[7] (2008:4)'.

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[6] National Cancer Registry (2008). Cancer projections 2005-2035: A Summary. National Cancer Registry, Cork. http://www.ncri.ie/pubs/pubfiles/CancerProjections2010-2035summary.pdf accessed 10th January 2011.

[7] Department of Health and Children. Tackling Chronic Disease - A Policy Framework for the Management of Chronic Diseases. Dublin, Stationery Office 2008

Appendix 7

HISTORY OF MID WEST PALLIATIVE CARE DEVELOPMENT

1. Background

Hospice services commenced in the Mid West Region in 1977 with the decision of the Little Company of Mary to open a 9-bed hospice unit within Milford House Nursing Home. Such a development was in keeping with the Order's mission of caring for the sick and the dying. Demand for the service grew and in the early 1980s plans for the development of a 20 bed purpose built hospice unit were finalised, the objective being to ensure the provision of a more comprehensive range of services throughout the Mid West Region. The Capital cost of this project, which at the time was some £0.7m. (€0.889m), was met in full through voluntary funding.

Over the period 1983 to 1988 working relationships between the Mid Western Health Board and Milford were being formalised but in many ways the potential benefits of palliative care service provision were underdeveloped. From early 1989, the Health Board, in conjunction with the Department of Health, became more actively involved with Milford on matters relating to the delivery and funding of Hospice/Palliative Care in the Mid West region.

In June 1989, Milford House commenced a Home Care Nursing Service, consisting of three nursing staff, financially supported by the Irish Cancer Society. The development of this service meant that, for the first time, specialist hospice nursing care was available to patients in their own homes, as well as ensuring additional direct support for carers. In December 1989, the Education Department at Milford was established and a needs assessment for day care services at Milford was undertaken in conjunction with the Health Board.

2. Working Party On Hospice Care 1990

The initial steps in formalizing a partnership arrangement between the Health Board and Milford House were taken in May 1990 with a decision to establish a Working Party on Hospice Care. It was composed of representatives of the Health Board, Milford House the Irish Cancer Society. Its task was to carry out a review of the existing range of Hospice Care services throughout the Mid West region and to make recommendations on their future development.

The Report of Working Party on Hospice Care (MWHB 1991) was published in February 1991, and was formally adopted as Health Board policy in June 1991. This report recognised Milford Hospice 'as being the major focus of Hospice Care in the Mid West region' (MWHB 1991:8) and it became stated Health Board policy to develop all future Palliative Care services in conjunction with Milford Hospice.

The following is a summary of the key recommendations:

- Milford Hospice should develop more fully its educational role for professionals and volunteers involved in the provision of Palliative Care services
- Milford Hospice should develop a Social Work/Bereavement Counselling service, and also expand its Pastoral Care services

- Milford Hospice should expand its Home Care service, through the appointment of additional Home Care Nurses at local bases in Nenagh, Thurles, Nenagh, Ennis and Newcastle West
- Milford Hospice should develop Day Care services as an integral part of its overall services
- A Consultant Physician in Palliative Medicine should be appointed in Milford Hospice with a direct link to Health Board Hospitals in the region
- A network of Hospice Support Beds should be established throughout the region with the objective of ensuring that all patients and families could avail of this back-up facility within a maximum 25 mile radius of their home
- A Steering Committee should be appointed, representative of the Health Board, Irish Cancer Society, Milford Hospice, local interest groups and General Practitioners that would be responsible for the ongoing co-ordination of services, policy evaluation / review.

Arising from this report a three year Action Plan was submitted to the Department of Health for additional resources, which resulted in the following expansion of services.

3. Developments 1991/1992

- Appointment of four additional Home Care Nurses working from bases in Nenagh, Thurles, Newcastle West, and Ennis (developments in North Tipperary at the outset were supported by the North Tipperary Hospice Movement)
- Appointment of an Education Co-ordinator at Milford Hospice
- Appointment of a Social Worker / Counsellor
- Appointment of a Pastoral Care Worker
- Establishment of a Regional Hospice Steering Committee
- Commissioning and funding of two support beds in the Hospice Unit in Cahercalla Community Hospital, Ennis, specifically for GMS patients
- Appointment of Associate Medical Officers in Co Clare, Limerick and North Tipperary, i.e. local G.P.s with a special interest / expertise in Palliative Medicine
- Physical development of additional accommodation at Milford Hospice to include Education, Bereavement Counselling, Home Care and other support elements.

4. Multi-Disciplinary Working

One of the key recommendations of the 1991 Report was that ways should be explored of improving the multi-disciplinary team working of all involved in the provision of palliative care. In 1993, the Health Board and Milford Hospice commissioned a research project on the workings of the multi-disciplinary team, to be conducted by the University of Limerick. The Report, Palliative Care in the Mid-West Region: A Multi-Disciplinary Team Approach, (MWHB 1995) was published in June 1995, and was adopted as Health Board Policy in July 1995.

The following is a summary of the key recommendations:

- Better co-ordination required in the area of Primary Care service in Palliative Care

- The need for the appointment of a Consultant Physician in Palliative Medicine, who would have a strong link with other Consultants/Hospitals in the Region
- Better co-ordination required in the area of inter-working relationships of Primary Care and Secondary Care services
- More information on services available needed for carers and professionals
- A broadening of the educational role at Milford
- The need for enhanced Social Work/Counselling services
- The need for additional Home Care Nurses
- The expansion of Palliative Care Services for non-cancer patients
- The need for further research in the area of Palliative Care
- The need to develop Day Care services at Milford.

5. 3-Year Action Plan

Arising from the recommendations of the 1991 Report, a small working group, representative of Milford Hospice and the Health Board, was set up in early 1996 in order to progress a 3-year Action Plan and to make recommendations on the future development of Milford Hospice as the regional service provider. A report from this Group was submitted to the Health Board May 1996 and then to the Department of Health for approval. This Report included proposals for the building of a 30-bed Specialist In-patient Unit at Milford and the development of Day Care and Educational facilities, at an estimated cost in excess of €6m. Indicative of the strengthening voluntary/statutory partnership arrangements between Milford and the Health Board, it was proposed that this development be funded on a 50:50 basis.

6. Policy Developments at National Level

It is worth noting that the Health Strategy, Shaping a Healthier Future: A strategy for effective healthcare in the 1990's (DoH 1994) made the first direct reference to Palliative Care and its future development.

A National Cancer Strategy, Cancer Services in Ireland: A National Strategy, (DoH 1996) was launched by the Minister for Health in 1996 and clearly supported the further development of palliative care services in Ireland.

In December 1996, approval was given by the Department of Health to the 30-bed Specialist In-patient Unit, thus allowing the proposed development at Milford to proceed. The building works commenced at Milford in January 1998 and were completed in 2000 at a total cost of €8.88m, at which point Day Care services also became operational.

7. Consultant Physicians in Palliative Medicine

In January 2000, the Region's first Palliative Medicine Consultant was appointed on a joint basis between Milford Hospice and the Mid Western Health Board. This was a very significant appointment, resulting in much benefit to Milford Hospice as the specialist service provider as well as assisting the further development of palliative care within the Health Board Acute Hospitals. Around this time, also, Clinical Nurse Specialists in Palliative Care were appointed to all Acute Hospitals in the area, which contributed to a greatly improved palliative care service within each hospital involved.

A second Consultant was appointed in December 2005 with sessional commitments to MCC and the MWRH.

A third Consultant is to be appointed during 2011 and will have sessional commitments to MCC and St. John's Hospital.

8. Summary of Other Developments

- Development of Support Bed Units in:
  - Dean Maxwell Community Nursing Unit, Roscrea in 1998 (2)
  - St Conlon's Community Nursing Unit, Nenagh in 2002 (2)
  - Kilrush, Ennistymon and Raheen, Co. Clare in 2004 (2 each)
  - Hospital of the Assumption, Thurles in 2004 (2)
  - Milford Care Centre, Limerick in 2007 (2)
  - St. Ita's Hospital, Newcastle West in 2008 (4 beds – revenue funding for opening of these beds is under discussion)
- Establishment by Health Board of Regional Consultative and Development Committees in Palliative Care in 2002
- Initiative in Bereavement Support for Children started in MCC
- Milford Care Centre accredited Stage 1 Nursing Development Unit in 2003
- Commencement of MCC Care Assistant at Home pilot initiative 2003/2004
- Publication of Palliative Care Needs Assessment for the Mid West and the Seven Year Strategic Plan for Palliative Care in the Mid West 2004 – 2011
- Commencement of MCC pilot project to provide night nursing support for patients with non-malignant conditions
- Establishment of the Health Service Executive in 2005
  - Transformation Programme 2007 – 2010
  - Reconfiguration of Acute Hospitals
  - Establishment of Directorate of Clinical Strategy and Programmes and Directorate of Quality Risk and Clinical Care
- Expansion of MCC Care Assistant at Home pilot initiative into full Hospice at Home service – commenced in 2006 and fully established by end of 2010
  - Closer links forged with the Primary Care Teams during this period
  - Evaluation of the project awarded to the University of Limerick
- Milford Care Centre accredited by the Irish Health Services Accreditation Board in 2007
- Integration of the ICS Night Nursing Service into MCC's Hospice at Home service on a pilot basis in 2010. Arrangement subsequently extended into 2011 and included in the evaluation of the Hospice at Home service
- Extension of Day Care from 2 to 3 days per week from the end of 2010
- Consortium Member of the All-Ireland Institute for Hospice and Palliative Care
- Education, Research and Professional Development Service established and range of courses provided significantly expanded
- Successful grant applications made to The Atlantic Philanthropies, JP McManus Pro-Am, Irish Cancer Society, Irish Hospice Foundation, Health Research Board
- Awarded hosting of Third International Conference on Public Health and Palliative Care to be held in 2013.